

D R A F T

FOR DISCUSSION ONLY

# MISUSE OF GENETIC INFORMATION IN EMPLOYMENT AND INSURANCE ACT

---

NATIONAL CONFERENCE OF COMMISSIONERS

ON UNIFORM LAWS

---

**For Drafting Committee Meeting February 10-12, 2006**

*WITH PREFATORY AND REPORTER'S NOTES*

Copyright © 2006

by

NATIONAL CONFERENCE OF COMMISSIONERS  
ON UNIFORM LAWS

---

*The ideas, concepts and conclusions set forth in this draft, including the proposed statutory language and any comments or reporter's notes, have not been reviewed, debated or approved by the National Conference of Commissioners on Uniform State Laws or the Drafting Committee. They do not reflect the views of the Conference and its Commissioners or the Drafting Committee and its Members and Reporter. Proposed statutory language may not be used to ascertain the intent or meaning of any promulgated final statutory proposal made by the National Conference of Commissioners on Uniform State Laws.*

January 31, 2006

**DRAFTING COMMITTEE ON MISUSE OF GENETIC INFORMATION IN  
EMPLOYMENT AND INSURANCE ACT**

D. JOE WILLIS, Pacwest Center, Suites 1600-1950, Portland, OR 97204, *Chair*  
JOANNE B. HUELSMAN, 235 W. Broadway, Suite 210, Waukesha, WI 53186, *Enactment Plan  
Coordinator*  
SHELDON F. KURTZ, University of Iowa, 446 BLB, Iowa City, IA 52242  
PETER F. LANGROCK, P.O. Drawer 351, Middlebury, VT 05753  
JAMES C. NELSON, Montana Supreme Court, 215 N. Sanders St., Room 425, P.O. Box 20031,  
Helena, MT 59601  
LINDA NEUMAN, 28218 218th St., LeClaire, IA 52753  
ARTHUR H. PETERSON, P.O. Box 20444, Juneau, AK 99802  
KEN H. TAKAYAMA, Legislative Reference Bureau, State Capitol, Room 446, Honolulu, HI  
96813  
JAMES A. WYNN, JR., NC Court of Appeals, P.O. Box 888, Raleigh, NC 27602  
JOAN ZELDON, District of Columbia Superior Court, 500 Indiana Ave. NW, Room 1640,  
Washington, DC 20001  
ELLEN DEASON, Ohio State University, 55 W. 12th Ave., Columbus, OH 43210, *Reporter*

**EX OFFICIO**

HOWARD J. SWIBEL, 120 S. Riverside Plaza, Suite 1200, Chicago, IL 60606, *President*  
MICHAEL B. GETTY, 1560 Sandburg Terr., Suite 1104, Chicago, IL 60610, *Division Chair*

**AMERICAN BAR ASSOCIATION ADVISOR**

ANNA MASTROIANNI, University of Washington, William H. Gates Hall, Box 353020,  
Seattle, WA 98195-3020, *American Bar Association Advisor*  
ROBIN S. SHAPIRO, 777 E. Wisconsin Ave., Suite 2000, Milwaukee, WI 53202, *American Bar  
Association Advisor*

**EXECUTIVE DIRECTOR**

WILLIAM H. HENNING, University of Alabama School of Law, Box 870382, Tuscaloosa, AL  
35487-0382, *Executive Director*

Copies of this Act may be obtained from:  
NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS  
211 E. Ontario Street, Suite 1300  
Chicago, Illinois 60611  
312/915-0195  
[www.nccusl.org](http://www.nccusl.org)

**MISUSE OF GENETIC INFORMATION IN EMPLOYMENT AND INSURANCE ACT**

**TABLE OF CONTENTS**

Prefatory Note ..... 1

**ARTICLE 1  
EMPLOYMENT**

SECTION 101. DEFINITIONS ..... 13  
SECTION 102. ACCESS TO GENETIC INFORMATION ..... 15  
SECTION 103. EXCEPTIONS THAT PERMIT GENETIC TESTING ..... 16  
SECTION 104. PROHIBITION ON USES OF GENETIC INFORMATION ..... 19  
SECTION 105. REMEDIES AND ENFORCEMENT ..... 20

**ARTICLE 2  
HEALTH INSURANCE**

SECTION 201. DEFINITIONS ..... 22  
SECTION 202. APPLICABILITY ..... 23  
SECTION 203. ACCESS TO GENETIC INFORMATION; PRIVACY ..... 23  
SECTION 204. LIMITATIONS ON USE OF GENETIC INFORMATION ..... 24  
SECTION 205. PREEXISTING CONDITION EXCLUSION ..... 25  
SECTION 206. PERMITTED INFORMATION ..... 25  
SECTION 207. ENFORCEMENT ..... 26

**ARTICLE 3  
LIFE, DISABILITY, AND LONG-TERM CARE INSURANCE**

SECTION 301. DEFINITIONS ..... 27  
SECTION 302. APPLICABILITY ..... 27  
SECTION 303. ACCESS TO GENETIC INFORMATION; PRIVACY ..... 28  
SECTION 304. LIMITATIONS ON USE OF GENETIC INFORMATION ..... 28  
SECTION 305. PREEXISTING CONDITION EXCLUSION FOR DISABILITY  
INSURANCE ..... 29  
SECTION 306. ENFORCEMENT ..... 29

# MISUSE OF GENETIC INFORMATION IN EMPLOYMENT AND INSURANCE ACT

## Prefatory Note

The scientific developments in the field of genetics are often characterized as a “revolution.” This revolution is ushering in a new era of greater understanding of human biological processes and the promise of new approaches to medicine that can tailor medical treatments to individuals’ genetic traits. Genetic tests also offer the possibility of identifying individuals who are at risk of developing certain diseases in the future. Unfortunately, while risk information has the potential to improve preventative medicine, it is also subject to misunderstanding and misuse.

There are important policy issues concerning the appropriate form and scope of regulation of genetic information. Perhaps it would be possible to agree on several underlying policy goals as a starting point. One proposal for appropriate goals is that (1) individuals should not be coerced into having genetic tests; (2) individuals who want to be tested should not be discouraged through fear of how the results will be used; (3) genetic information should not be used for irrational discrimination, that is, where there is no scientific basis for discrimination; and (4) even “rational” discrimination should be prohibited when it violates public policy, including the policy of preventing discrimination on the basis of disability. Cynthia Nance, Paul Miller, & Mark Rothstein, *Discrimination in Employment on the Basis of Genetics*, 6 Employee Rights & Employment Policy Journal 57, 79 (2002).

Another commentator phrases these goals in a similar way, with a proposal that regulation is justified: (1) to protect the few people whose genetic inheritance puts them at risk for rational genetic discrimination; (2) to protect those who are at risk of irrational genetic discrimination; and (3) to allay public fears that could impede genetic research. Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1500 (2001). One might also add an additional goal to treat individuals with respect by maintaining the privacy of their genetic information.

The point about irrational discrimination needs elaboration. Because the human genome has been portrayed with images such as “blueprint,” “code,” and “future diary,” public misunderstandings of the role of genetics are common. Employers and insurers cannot be expected to be exempt from such misunderstandings, which may cause them to exaggerate the predictive potential of genetic information.

There are some rare genetic diseases, such as Huntington’s disease, that are caused by a single gene and that can be predicted with certainty by an individual’s genetic sequence. These are the diseases that arguably justify “rational” discrimination. But such monogenetic diseases are the exception. They have received much attention as the first diseases for which researchers established a genetic link, but they afflict relatively few individuals. And even with such diseases, there is usually variation in the age that symptoms appear and in their severity.

The genetic causation of most diseases is far more complex. It is more common for medical conditions to result from interactions among multiple genes and with the environment. Most of the diseases that are linked to a genetic variation do not appear in all of the individuals with that genotype. This is termed “incomplete penetrance.” For example, certain forms of the BRCA 1 gene are strongly associated with susceptibility to breast cancer. But only 50-85% of women who have this form of the gene will ever develop the disease. Moreover, the frequency of particular gene variants and their degree of penetrance often differ among ethnic groups, which also complicates the clinical sensitivity of genetic tests and their predictive capabilities.

Another complicating factor for accurate prediction is that often a large number of genetic variations can cause the same disease. More than 180 different sequences of beta-globin genes are associated with the blood disease beta-thalassemia. And the severity of the symptoms of patients with this disease vary dramatically. Similarly, there are more than 300 forms of the gene responsible for cystic fibrosis. Unfortunately, identifying the variant of the gene does not explain the variation in symptoms.

Low penetrance, multiple genetic variations that may cause a single disease, and other sources of complications diminish the predictive value of genetic testing. In addition to the over-inclusiveness of many medical predictions based on genetic tests (in that a person with a predisposing genotype may never have symptoms of the disease), genetic predictions are also often extremely under-inclusive. For example, the predisposing variants of the BRCA 1 and BRCA 2 genes are present in only 5 to 10% of breast cancer patients. Thus genetic data often do not provide an accurate individualized prediction. This is a major justification for the regulation of genetic information.

Many of the existing state statutes on use of genetic information fall into three general categories: employment, health insurance, and other insurance, usually life, disability and/or long-term care. There is some overlap, but often states treat each of these areas somewhat differently. Therefore, for ease of initial consideration, the draft is organized in three separate articles corresponding to these topics.

It is important to remember, however, that some states have statutes that cut across all three areas and govern other topics as well. For example, statutes that concentrate on genetic testing or genetic privacy typically apply to issues of consent, disclosure, retention of samples, use of genetic material, and/or use of databases generally. These issues have applications beyond the context of employment and insurance, and will be relevant to the Conference’s decisions on the eventual scope of the Act.

Other issues also cut across the three main areas of state genetic legislation. There is a major policy debate over the wisdom of “genetic exceptionalism”—the regulation of genetics testing and information as a special category rather than as part of more comprehensive regulation of medical testing and information. *See generally* T.H. Murray, *Genetic Exceptionalism and Future Diaries: Is Genetic Information Different from other Information*, in

Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (Mark A. Rothstein ed. 1977); Sonia M. Sutter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 Wash U. L.Q. 669 (2001).

In the course of this debate, many arguments for singling out genetics for special attention have been raised and rejected. In the early 1990s, The Task Force on Genetic Information and Insurance, a joint working group of the National Institutes of Health and the U.S. Department of Energy, considered and rejected three justifications for such a policy. 1) They decided that genetic information is not sufficiently distinct from other health information on the basis of its prophetic potential. Genetic predispositions can be affected by many factors and information on non-genetic characteristics, such as lifestyle, may be better health predictors. 2) Genetic information is also not unique in its implications for family members. 3) And genetic information is not the only type of health information with the ability to stigmatize.

Other arguments for exceptionalism include that genetic information is particularly sensitive in that it identifies normal variations that fuel discrimination despite their lack of clinical significance. Genetic codes are also viewed as immutable, so that one test can follow a person forever, and genetic information is more probabilistic than other types of medical information. These arguments can also be refuted as a basis for exceptionalism on the ground that they apply as well to other types of health information. Laine Friedman Ross, *Genetic Exceptionalism vs. Paradigm Shift: Lessons from HIV*, 29 J. L. Med. & Ethics 141 (2001).

There are also objections to treating genetic information separately on practical grounds. The distinction between genetic and non-genetic disorders is increasingly difficult to draw; most conditions have both a genetic and non-genetic component. Opponents of exceptionalism also contend that it is unrealistic to separate genetic information in medical records, so that it would be impossible to comply with restrictions on disclosing genetic information to employers or insurers. L.O. Gostin & J.G. Hodge, *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 *Jurimetrics* 21 (1999). Also, there is a social argument that it is unwise to enact laws that treat genetic conditions as if there is a stigma attached to them because that reinforces such attitudes and becomes a self-fulfilling prophecy. Moreover, treating genetics as unique only encourages the public view that genetics exert a special control over our lives, a view termed “genetic essentialism.” See, e.g., Rochelle Cooper Dreyfus & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 *Vand. L. Rev.* 313 (1992).

Most of the opponents of genetic exceptionalism do not oppose privacy protections, rather they advocate more holistic approaches to health information and its use in employment and insurance. The larger debate is about how to protect medical data from harmful uses while providing access for uses that individuals, clinicians, and society regard as beneficial. Genetic information is one part of the problem posed by the ease of collecting, storing and disseminating personal information. Thus it is possible to argue that the exceptionalism debate is a distraction from the more important questions about how regulations should be adapted to new scientific developments. Zita Lazzarini, *What Lessons Can We Learn from the Exceptionalism Debate*

(Finally)?, 29 J. L. Med. & Policy 149 (2001). In the context of health insurance, one commentator maintains that “[g]enetic equity should be regarded not as an exceptional goal, but as an aim consistent with a broader movement toward equitable access to health care in a time of scarcity.” John V. Jacobi, *Genetic Discrimination in a Time of False Hopes*, 30 Fla. St. U. L. Rev. 363, 364 (2003).

Scientific advances in genetics mean that a very large amount of information can be obtained from one small sample that is easily obtained and analyzed, yielding data that is easily stored and disseminated. This is not unique, but the concentration of information makes genetic information, which combines the power of many other types of medical information, seem particularly threatening. The drafting committee’s charge responds to the large number of states that have enacted legislation dealing with the threats associated with genetic information. That legislation is highly inconsistent and often deals only partially with the issues. The charge does contemplate genetic exceptionalism by focusing on use of genetic information rather than on health information or privacy more generally. Broader measures for all medical information may not be practical at this time. Nonetheless, it is still important to respond to problems with the use of genetic information. Perhaps regulation of the use of genetic information can serve as an example for policies that need to be developed for the treatment of medical information more generally.

## Employment

### *General Policy Issues*

Many contend that genetic information has few appropriate uses in the workplace. The concern is that if employers are permitted consider genetic information in making personnel decisions, individuals may be unfairly barred or dismissed from employment for reasons that are not related to their ability to do the job. This is an especially high risk with predictive genetic information because so many persons tend to exaggerate the role of genes in disease and mistakenly regard an increased risk of an illness as a certainty that it will occur.

Employers arguably have an economic incentive to use genetic information to avoid hiring employees with higher medical insurance claims, higher absenteeism, or lower productivity. They may also wish to avoid the effect of high health care costs incurred by employees’ dependents. Somewhat perversely, because the federal Health Insurance Portability and Accountability Act (HIPPA) protects employees against discrimination in group health insurance based on medical conditions, including genetic characteristics, the most effective way for employers to avoid high insurance costs is to screen applicants and avoid hiring high-risk individuals. Nonetheless, there are few well-documented cases of genetic discrimination in employment.

In 1996, the NIH-DOE Joint Working Group on Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group) and the National Action Plan of Breast

Cancer developed and issued the following recommendations for state and federal policy makers to protect against genetic discrimination in employment. To a large extent, these recommendations mirror the approach of the Americans With Disabilities Act, described below.

- Employment organizations should be prohibited from using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits or termination of employment unless the employment organization can prove this information is job related and consistent with business activity.
- Employment organizations should be prohibited from requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment, and under all circumstances, employment organizations should be prohibited from requesting or requiring collection or disclosure of genetic information unless the employment organization can prove this information is job related and consistent with business necessity, or otherwise mandated by law. Written and informed consent should be required for each request, collection or disclosure.
- Employment organizations should be restricted from access to genetic information contained in medical records released by individuals as a condition of employment, in claims filed for reimbursement of health care costs and other sources.
- Employment organizations should be prohibited from releasing genetic information without prior written authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure will be made.
- Violators of these provisions should be subject to strong enforcement mechanisms, including private right of action.

Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 Science 1755 (1996).

### *The Federal Regulatory Context*

The states are legislating in a regulatory environment in which two federal statutes provide modest legal protections against discrimination in employment on a genetic basis: Title VII of the Civil Rights Act of 1964 (Title VII) and the Americans with Disabilities Act (ADA). These statutes are also important because many states have their own version of the legislation which they have modified to incorporate genetic protections.

Title VII prohibits employer discrimination on the basis of race, sex, color, national origin, and religion. It is applicable to genetic discrimination if an employer tests a group of employees in one of the protected classes. For example, the court in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260 (9th Cir. 1998), held that testing only black



employees for the sickle cell trait violated Title VII by imposing a condition of employment on the basis of race. It is also possible that testing all employees could violate the Act if the test were for a trait closely associated with a protected group, such as sickle cell trait (which is more prevalent among African-Americans) or Tay-Sachs disease (associated with Ashkenazi Jewish ancestry). However, in these circumstances the statute would require the difficult showing that the testing was a pretext for intentional discrimination against the group or that it had a statistically significant disparate impact on employment opportunities of members of the group. Most importantly, the narrow focus on employers' actions with respect to certain groups means that Title VII would certainly not apply if an employer instituted a screening program for traits that are not strongly associated with a protected group. *See* Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).

The ADA could provide some protections against genetic discrimination through its regulation of disability discrimination, although this potential is limited by the Supreme Court's narrow interpretation of the statute. *See, e.g., Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 484-85 (1999) (stating ADA is intended to have limited coverage). "Disability" is defined under the ADA as (1) a physical or mental impairment that substantially limits one or more of the major life activities of an individual; (2) a record of such impairment; or (3) being regarded as having such an impairment. 42 U.S.C. § 12112(d)(2). If a genetically-caused disease results in a disability under the first prong of the definition, the ADA's protections will apply. The genetic connection is irrelevant; the statute protects the person because of his or her disability, not its cause. Similarly, under the second prong the ADA covers individuals with a prior record of a genetically-related disability, such as a person recovering from a cancer. Of course, if these genetic conditions do not qualify under the definition of "disability" by substantially limiting a major life activity, the individual is not covered by the ADA.

The application of the ADA to discrimination based on a genetic trait that is not manifested in symptomatic disease is a more difficult question. In 1995 the EEOC issued a policy statement that an individual should be "regarded as" having a disability under the statute's third prong if the employer discriminates on the basis of "genetic information relating to illness, disease, or other disorders." EEOC Order No. 915.002 § 902 (1995). This interpretation of the statute has not been considered by the courts, although several U.S. Supreme Court Justices have expressed their disapproval in dicta. *See, e.g., Bragdon v. Abbott*, 524 U.S. 624, 661 (1998) (Rehnquist, J., joined by Scalia, J. & Thomas, J., concurring in part & dissenting in part). Moreover, the EEOC's position has been criticized in both conceptual and practical terms. *See, e.g., Pauline T. Kim, Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).

The ADA protects a disabled job applicant or employee from discrimination in the workplace. This includes a duty to provide reasonable accommodations to a qualified individual with a disability unless the accommodation would impose an undue hardship on the operation of the business. The ADA also regulates testing and access to information by prohibiting medical

examinations or testing prior to a job offer. However, after making a “conditional offer,” an employer may require an applicant to take a medical exam. Employers also have the right at that point in the hiring process to require that individuals sign a blanket release disclosing all their medical records to the employer. Employers may also test existing employees if they can justify the testing as job-related. Thus, despite the ADA’s protections against discrimination through its requirements for reasonable accommodations, the ease of employer access to medical information may deter individuals from obtaining testing.

### *Current State Statutes*

Concern about economic incentives for employers has led 34 states (at last count) to enact statutes that regulate the use of genetic information or genetic testing by employers. One group of states has used an existing state statute as a platform, amending it to apply to genetic testing or information. A second, larger, group has enacted statutes that are specifically tailored for genetic issues.

In the first group, some states have extended their disability statutes to prohibit discrimination by employers based on genetic information under the rubric of disability. *See, e.g.*, Hawaii RS §§ 378-1 to 378-6; Illinois, 410 ILCS 513/5 to 513/30 (tied to federal Americans with Disability Act); Mich Comp Laws Ann §§ 37.1201-37.1202; NY Exec Law §§ 292, 296 (adds genetic conditions to the definition of protected disability).

Other states have built on their statutes prohibiting discrimination in employment, expanding them from race, sex, national origin, etc., to include discrimination based on genetic information. *See, e.g.*, Ariz Rev Stat Ann § 41-1463; Cal Govt Code §§ 12926, 12940; Conn Gen Stat Ann § 46a-60; Mass Gen L ch 151B; Nev Stat § 613.345; NJ Stat Ann §§ 10:5-5, 10:5-12.

Wisconsin has used its Fair Employment Act as its vehicle, amending it to restrict the ability of employers to conduct genetic testing and use genetic information. Wis Stat § 111.372.

States in the second group have enacted special statutes that regulate genetic testing and/or the use of genetic information. This is the largest group of states, but the extent to which they concentrate on the context of employment varies to some extent. Most commonly, the provisions are tailored specifically for employment. *See, e.g.*, Ark Code Ann §§ 11-5-401 to 11-5-405; Del Code Ann § 710; Kan Stat Ann §§ 44-1002(m), 44-1009(a)(9); La Rev Stat Ann §§ 23.302, 23.368-369; Iowa Code § 729.6; Me Rev Stat Ann tit 5, § 19301; Md Code Ann art. 49B §§ 15,16; Minn Stat § 181.974; Neb Rev Stat § 48-236; NH Rev Stat Ann §§ 141-H:1 to 141-H:5; NC Gen Stat § 95-28.1A; Okla Stat tit 36, § 3614.2; Or Rev Stat § 659A.300; RI Gen Laws §§ 28-6.7-1 to 28-6.7-4; S.D. codified laws §§ 60-2-20 to 60-2-21; Tex Lab Code Ann § 21.401; Utah Code Ann §§ 26-45-101 to 26-45-106; Vt Stat Ann tit 18, §§ 9331-9335; Va Code Ann § 40.1-28.7:1(A); Wash Rev Code Ann § 49.44.180. Some statutes cover genetic information more broadly, regulating its use in employment along with insurance and other activities. *See,*

*e.g.*, N Mex Stat Ann § 24-21-2. For other statutes, the focus is on broad regulation of genetic testing and information, with coverage that applies to employers along with others who might use the information. *See, e.g.*, Fla Stat § 760.4; NJ Stat Ann § 10:5-44, Or Rev Stat § 192.537.

The states that have special statutes limiting genetic testing or the use of genetic information in the employment setting have obviously embraced exceptionalism. But so, for the most part, have the states that have added discrimination based on genetic information to their employment discrimination statutes. This is the case because genetic characteristics are singled out and treated differently from other medical conditions under these statutes. An exception is California, whose statute prohibits employment discrimination on the basis of medical conditions in addition to the more traditional categories of race, sex, national origin, etc. Under this statutory scheme, a genetic characteristic is treated as a medical condition and receives the same protections as other health problems. Finally, disability statutes by definition single out certain types of medical conditions (those that are disabling because they limit a major life activity) for special protection. When genetic predispositions or conditions are defined as disabilities, they are treated similarly to this class of medical conditions. However, to the extent that a genetic condition does not fit within the rubric of “limiting a major life activity,” it is being treated differently from other non-disabling medical conditions under these statutes.

## Health Insurance

### *General Policy Issues*

Discrimination in health insurance is a uniquely American problem because the United States does not guarantee coverage of health care expenses for its citizens as other wealthy nations do. Legislation in this area responds to public perceptions that health insurers will deny coverage or increase premiums based on predictive genetic information. This may be irrational discrimination. In addition, individuals who fear reduced or more expensive health care coverage may avoid genetic tests that could provide useful information for improving their health. The legislative restrictions are designed to avoid these outcomes.

The main argument against regulation in this market is that genetic information would allow insurers to decrease adverse selection. Adverse selection is the disproportionate purchase of insurance by individuals who have medical reasons to believe they will need to make claims. It leads to insurer losses when applicants fail to disclose the relevant health information and is a particular concern with individual health insurance policies. The industry and a number of scholars contend that avoiding losses due to adverse selection based on genetic information will lead to more affordable insurance.

In 1995, the NIH-DOE Joint Working Group on Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group) and the National Action Plan of Breast Cancer developed and issued the following recommendations for state and federal policy makers to protect against genetic discrimination in health insurance. The recommendations apply to both

group and individual health plans.

- Insurance providers should be prohibited from using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment or contribution requirements.
- Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.
- Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information.
- Insurance providers and other holders of genetic information should be prohibited from releasing genetic information without prior written authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure would be made.

Kathy Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 Science 392 (1995).

One study of state restrictions on the use of genetic information in health insurance concluded that there are almost no well-documented cases of insurers asking for genetic test results for pre-symptomatic conditions in either states with regulation or states without such regulation. The author argued that use of genetic information is not cost effective and is not seen by insurers as increasing the accuracy of their underwriting. Nonetheless, he believes that state laws will have an effect by making it less likely that insurers will use genetic information in the future, because the laws have helped convince them that use of this information is not socially acceptable. Mark A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information*, 40 *Jurimetrics J.* 93 (1999).

### *The Federal Regulatory Context*

As with employment, the states legislate against the background of federal statutes. The 1996 federal Health Insurance Portability and Accountability Act (HIPPA) partially addresses the use of genetic information in health insurance. It covers only insurers providing group health insurance for 50 or more individuals. Under HIPPA, an insurer may not deny an applicant coverage as a result of a health-status related factor, including genetic information. The law also prohibits exclusions for pre-existing conditions on the basis of a genetic predisposition to a particular condition. However, employers may restrict coverage, restrict benefits, or charge higher premiums so long as they treat like individuals alike.

The federal legislation regulates only a portion of the health insurance market. It does not apply to employees in small group health insurance plans or to individual health insurance

coverage. In addition, there is no federal provision on the use of genetic information in health insurance for employees covered by self-insured health plans, which are used by most large employers. These plans are subject to the federal Employee Retirement Income Security Act (ERISA), which preempts state regulation of employer sponsored welfare benefit plans.

### *Current State Statutes*

The law in 47 states restricts the use of genetic information by health insurers in some way. Some states impose restrictions only on group health insurance (Ak, Iowa, SD, Wy), and some only on individual policies (Hawaii, Nebraska, WV), but most cover both group and individual health insurance.

There are five main types of state regulation of genetics in health insurance. First, many states prohibit insurers from requiring individuals to have genetic tests or to disclose genetic information to the insurer. (Ark, Cal, Col, Fla, Ga, Haw, Ill, Ind, Kan, Md, Mich, Minn, Mo, Montana, Neb, NH, NMex, NY, OH, OK, Or, RI, SD, Tenn, UT, Wis). In a few states (Mich, Neb) this restriction on access to information stands alone, but most states have additional measures.

Second, a number of states prohibit health insurers from disclosing genetic information without informed consent. (Ariz, Cal, Col, Del, Ga, Haw, Ill, Ky, La, Me, Md, Mass, Mich, Mo, Nev, NH, NJ, NMex, NY, Or, RI, SC, Tenn, Tex, Vt, Va, Wash).

In addition to these privacy-based protections, there are also restrictions on health insurers' use of genetic information. In a third category, a large number of statutes provide that insurers may not establish rules for eligibility (i.e., deny coverage) based on genetic information. (Alaska, Ariz, Ark, Cal, Col, Conn, Del, Fla, Ga, Haw, Ill, Ind, Iowa, Kan, Ky, La, Me, Mass, Minn, Mo, Mont, Nev, NH, NJ, NMex, NY, NC, OH, OK, Or, RI, SC, SD, Tenn, Tex, UT, Va, WV, Wis, Wy).

Fourth, most of these same states impose some type of limit on the use of genetic information for risk selection or classification in health insurance. (i.e., higher premiums, reduced coverage or reduced benefits). Many states simply prohibit insurers from considering genetic information for these purposes.

Fifth, some states do not permit health insurers to impose pre-existing condition exclusions based on predictive genetic information in the absence of a diagnosis based on symptoms of the disease or condition. (Alaska, Conn, Idaho, Iowa, Ky, others ).

This draft does not consider the emerging health issue of access to genetic services and insurance coverage for their costs. Currently the states with laws in this area cover newborn screening and genetic childhood diseases. According to the National Conference of State Legislatures, no state currently requires coverage of testing for adult onset genetic disorders such

as breast cancer, but bills are being introduced frequently.

## Life, Disability and Long-Term Care Insurance

### *General Policy Issues*

Life, disability and long-term care insurance can be distinguished from health insurance in that a greater proportion of the market consists of individual policies rather than group coverage. According to the National Conference of State Legislatures, approximately 60% of life insurance, 40% of disability insurance, and almost all of long-term care insurance is underwritten individually, compared to only about 10% of health insurance. Individual underwriting decisions are based on an individual's characteristics rather than broader group characteristics, so there would be more value in knowing individual genetic information if it could accurately predict the likelihood of claims.

The argument for restricting access to genetic information is that its predictive power is easily exaggerated and insurers may force applicants to take genetic tests and then deny insurance or charge more based on genetic characteristics. This raises the possibility that a large class of people will lack coverage even though they are not sick. On the other side, as with health insurance, insurers worry about adverse selection. If applicants seek coverage because a genetic characteristic exposes them to risk, but the insurer does not have this information, this puts the insurer at a financial disadvantage. *See generally* Mark A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy* (2004).

A 1997 study by the Human Genetics Advisory Commission in the United Kingdom concluded that it is unlikely that actuarially-sound genetic predictions of adult death will be validated and available anytime in the near future. Genetic tests need to be connected to medical and epidemiological research to establish what consequences for health and life-span can be inferred from a given genetic test. The Commission concluded that a requirement to disclose genetic tests as a condition of obtaining insurance would be acceptable only after research has established an association between a given pattern of test results and life events that are relevant for the insurance product. They recommended continuing a moratorium on requiring test results and predicted that the life insurance industry could withstand the limited adverse selection that might result from non-disclosure. Human Genetics Advisory Commission, *The Implications of Genetic Testing for Insurance* (1997).

### *Current State Statutes*

Eighteen states have legislation regulating genetic testing or the use of genetic information in life, disability or long-term care insurance. Of these 18, only 8 have provisions that apply to all three types of coverage. Sixteen statutes that pertain to life insurance, sixteen apply to disability insurance, and nine cover long-term care insurance. While many of the other states are silent on genetic information in the context of these types of insurance, some make

clear that their restrictions on the use of genetics in health insurance do not apply to other insurance. (Ga, Ind, NH, OK, RI, Tex).

In the life insurance category, several of the states forbid insurers from requiring genetic tests and regulate the terms under which an insurer may disclose the results of voluntary tests. (Cal, Mass, Minn, NY, Or, Vt). Other states require an actuarial justification for using genetic information in denying coverage or underwriting, which means the insurer must be able to demonstrate a significant difference in claims due to a particular genetic condition. (Ariz, Kan, Maine, Md, Mass, Mont, NJ, Nmex, Vt, Wis). Florida and North Carolina prohibit discrimination based on the sickle cell trait.

Provisions are similar among the states that regulate disability insurance. States tend to prohibit insurers from requiring tests (Cal, Mass, Or), restrict use of information for eligibility and underwriting (Kan, Wy), or require actuarial justification for underwriting discrimination (Ariz, Maine, Mass). A few states impose conditions similar to those more commonly applicable to health insurance. They prohibit insurers from rejecting applicants for disability insurance (Arizona) or imposing limitations on coverage for pre-existing conditions (Idaho, Wyoming) on the basis of a genetic characteristic unless it has resulted in a diagnosed condition.

The pattern of regulation is similar, but less common, for long-term care insurance. Some states prohibit insurers from requiring genetic tests (Cal, Mass, Or, Vt) or require an actuarial justification for the use of genetic information in underwriting (Kan, Maine, Mass, Mont, NMex).





1 **Reporter’s Notes**

2  
3 The definitions used in the Act will obviously greatly affect its scope. One major concern  
4 is that the definitions should be crafted so that they do not become obsolete or unintentionally  
5 limited by advances in science. As a starting point, the definitions are not limited in terms of  
6 substances that provide information about a person’s genetic makeup (such as DNA and RNA) or  
7 particular types of tests, as these may change with scientific and medical developments.  
8

9 *Subsection (2).* Family members are defined broadly to encompass both those whose  
10 genetic information might have implications for an employee or applicant and those whose  
11 medical conditions could affect employer health care costs.  
12

13 *Subsection (3).* The definition of “genetic information” selected as a starting point for the  
14 draft is modeled on the type of definition that has been chosen by the greatest number of states in  
15 that it includes information on genetic characteristics broadly, whether it is obtained from tests or  
16 family medical history. (Cal, Conn, Hawaii, LA, Maine, MD, Mass, Mich, NJ, NMex, NC, RI,  
17 SD, TX, WA). A smaller number of states limit protected genetic information to the results of  
18 laboratory genetic testing only, either of the individual employee (Ark, Del, Neb, NH, NY, OK,  
19 VT), or of the employee and blood relatives (LA, Minn, Or, UT).  
20

21 *Subsection (5).* The definition for “genetic test” was crafted to avoid a link to disease.  
22 While most of the reasons an employer might currently discriminate based on genetic  
23 information probably involve a disease, disorder, or impairment, this may not always be the case.  
24 One can imagine, for example, that the presence or absence of behavioral traits might also be a  
25 criterion for selecting an employee. While the current evidence linking behavior to genes is  
26 tenuous, this area continues to be the subject of investigation. Moreover, a broad definition of  
27 testing would facilitate the eventual application of the statute to topics outside employment and  
28 insurance, if that is the direction the Conference takes. For example, provisions governing the  
29 retention of samples used for research or identification would involve testing that is not  
30 necessarily linked to disease. A few states, including some with newly enacted or amended  
31 statutes, already have definitions that do not limit genetic testing to the diagnosis of diseases or  
32 impairments. (Fla, Haw, Mass, NH, Ore, SD?, UT).  
33

34 The statutes that more narrowly contemplate testing for disease-related genes fall into two  
35 groups. One set of states appears to regulate tests and the use of information concerning either a  
36 symptomatic genetic disease *or* an increased risk of future disease. (Ariz (disclosure statute), Ill,  
37 Iowa, Kan, LA, Mich, Nev, Minn, NY, OR, RI, VT, VA, WI). Not all these statutes are specific  
38 or clear on this aspect of their scope. The other set of states excludes current diseases and  
39 conditions, limiting coverage to asymptomatic persons with a predisposition, propensity,  
40 susceptibility or increased risk. (Ariz (disability statute), Ark, Del, Maine, MD, Minn, MO, Neb,  
41 NJ, NM, NC, OK, TX).  
42

43 Some of the state definitions specifically include testing for the purpose of monitoring for

1 genetic damage through workplace exposure. (Ariz, Ill, N.Mex). Rather than defining this as a  
2 type of testing, the draft treats this as a permitted version for testing in section 103.  
3

4 *Subsection (6).* The definitions in the draft are designed to allow tailoring of the scope of  
5 prohibitions and permitted uses of information. A “predisposing genetic characteristic” is only  
6 predictive of a future health condition. This term does not refer to genetic characteristics that are  
7 manifest in a disease, medical condition or disability. The broader terms “genetic test” and  
8 “genetic information” include both predisposing and manifest genetic characteristics as well as  
9 genetic information that does not necessarily pertain to health.  
10

## 11 **SECTION 102. ACCESS TO GENETIC INFORMATION.**

12 (a) An employer may not request or require an individual or an individual’s  
13 family member to take a genetic test as a condition of the individual’s employment.

14 (b) Except as provided in Section 103, an employer may not request or require an  
15 individual or an individual’s family member to provide genetic information.

16 (c) An employer may not inquire whether an individual or an individual’s family  
17 member has taken a genetic test, refused to take a genetic test, or accessed genetic services.

### 18 **Reporter’s Notes**

19  
20 Employers get health information in a variety of lawful ways including applications,  
21 interviews, references, post-offer medical exams, post-offer releases of medical records, Family  
22 and Medical Leave Act requests, worker’s compensation claims, health insurance claims to self-  
23 insured employers, and voluntary disclosures by employees. As a result, many states have tried  
24 to limit employer access to genetic information in order to make genetic discrimination less  
25 likely. Unlike discrimination based on sex or race, an employer cannot discriminate on the basis  
26 of genetic characteristics unless it has access to genetic information. Many state’s statutes  
27 prohibit an employer from requiring, requesting or administering genetic testing, obtaining  
28 genetic information, making inquiries about genetic information, or some combination of these  
29 methods of accessing genetic information. (Conn, Del, Iowa, Kan, MD, Mass, Mich, Minn, Neb,  
30 Nev, NH, NY, OR, RI, Tex, UT, VT, VA, WA, WI).  
31

32 In addition, even if an employer does not use the information to discriminate, many  
33 believe that an employee should be able to keep genetic information private. Scholars have  
34 argued that a privacy rationale makes more sense for protecting genetic information in the  
35 employment context than an anti-discrimination rationale. The anti-discrimination rationale

1 emphasizes an employer’s intent, and protections based on this rationale are designed for socially-  
2 recognized groups that have been historically disadvantaged. Genetics do not fit especially well  
3 within this paradigm. *See, e.g.,* Pauline T. Kim, *Genetic Discrimination, Genetic Privacy:*  
4 *Rethinking Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).  
5

6 In some states access provisions for genetic information contain a major loophole that  
7 corresponds to a gap in federal coverage. Most of the states that rely on disability statutes  
8 provide exceptions for testing that conform to the pattern of the ADA and thus allow testing of  
9 an applicant and access to an applicant’s medical records after a conditional offer of  
10 employment. This approach opens the door broadly to genetic information. In contrast, the draft  
11 of this section broadly prohibits such access, subject to exceptions for particular situations in  
12 Section 103. (Alternatively, California and Minnesota have addressed this problem  
13 comprehensively by providing that employers may not have access to non-job related medical  
14 information at any time.)  
15

16 An important issue in employer access to genetic information is the role that employee  
17 consent should play. Should employers be able to seek out genetic information, by testing or  
18 accessing existing data, if an employee provides consent? Some states permit this. (Fla, Mass,  
19 NH, NJ). (Massachusetts takes a more general approach that avoids genetic exceptionalism:  
20 disclosure of health care records to employers without the informed consent of the employee is  
21 prohibited in general, including the disclosure of genetic information.) These statutes appear to  
22 assume that such consent is voluntary. It is possible, however, to argue that in the context of at-  
23 will employment, the need to retain one’s job may turn an employer’s request for genetic  
24 information into a demand that an employee dare not refuse. Thus many of the statutes prohibit  
25 even requests or inquiries. This draft follows that approach. A more stringent level of protection  
26 could protect workers from ever providing genetic information, even on their own initiative. But  
27 that arguably goes too far because it would prevent an employee from sharing information that  
28 could be used to protect him or her from situations in which the employee is genetically  
29 susceptible to harm. Thus the following section permits employee consent for testing in limited  
30 circumstances.  
31

32 **SECTION 103. EXCEPTIONS THAT PERMIT GENETIC TESTING.**

33 (a) If an employee requests a genetic test and provides written informed consent,  
34 an employer may conduct genetic testing for the purpose of:

35 (1) determining an employee’s predisposing genetic characteristics that  
36 may create susceptibility to harm from a workplace substance;

37 (2) monitoring the results of an employee’s exposure to a harmful

1 workplace substance; or

2 (3) investigating a worker's compensation claim.

3 (b) An employer may not terminate an employee or take adverse employment  
4 action against an employee as a result of a test performed under this section.

5 (c) An employer conducting genetic testing under this section shall report the  
6 results to the employee and a health care professional designated by the employee.

7 (d) An employer conducting a genetic monitoring program may receive the  
8 genetic testing results only in an aggregate form that does not disclose the identify of specific  
9 employees.

### 10 **Reporter's Notes**

11  
12 *Subsection (a)(1), (2).* Determining employee susceptibility to harm from exposure to  
13 workplace substances is one situation in which it might be appropriate to permit employee  
14 testing. This situation is illustrated by chronic beryllium disease. Beryllium is a lightweight  
15 metal used in many industries that poses the threat of this disease when dust or fumes are  
16 inhaled. Industry protections have greatly reduced exposure, but a small portion of the  
17 population can contract the disease even after a very brief exposure. A genetic marker has  
18 reportedly been identified for this extreme sensitivity that purports to show with certainty which  
19 individuals will contract beryllium disease and die from short exposure. Cynthia Nance, Paul  
20 Miller, & Mark Rothstein, *Discrimination in Employment on the Basis of Genetics*, 6 Employee  
21 Rights & Employment Policy Journal 57, 63-64 (2002). If so, testing could provide information  
22 that could define an individual's risk from workplace exposure to beryllium.

23  
24 Monitoring for damage to an individual's genes from harmful workplace exposure is  
25 another possible justification for testing.

26  
27 While privacy advocates might seek to draw a bright line and avoid any genetic testing,  
28 several states provide exceptions that permit testing by the request of an employee for purposes  
29 of determining susceptibility or monitoring. (Iowa, LA, NH, NY, WI). More generally, the  
30 definitions and prohibitions many state's statutes do not appear to restrict monitoring for genetic  
31 damage, or are ambiguous on this issue.

32  
33 One approach to allowing exceptions permits an employer to require testing in limited  
34 circumstances. Under the ADA and most state statutes modeled on it, an employer can obtain

1 medical information about its employees if it has a reasonable belief that (1) the employee will be  
2 unable to perform the essential functions of his or her job due to the medical condition or (2) the  
3 employee will pose a direct threat to health or safety because of the medical condition. This  
4 standard places the burden on the employer to show that it is relevant to test for a particular  
5 genetic marker in the context of an asymptomatic genetic disorder. Many commentators agree  
6 that this would be a difficult burden to meet.

7  
8 Similarly, states that have amended their employment discrimination statutes to include  
9 genetics usually follow the rubric of those statutes and permit testing or collection of genetic  
10 information when it is relevant to job-related qualifications or justified by business necessity.  
11 Other states with stand-alone genetic statutes have also adopted this approach. (Del, NH, NY,  
12 Or). The meaning of these standards in the context of genetic information is often not clear, but  
13 some states specify that a condition is job-related and testing is consistent with business necessity  
14 only under narrow circumstances. For example, Delaware defines these standards using  
15 language similar to the ADA.

16  
17 Rather than allowing an employer to compel testing under these circumstances, the draft  
18 of this section uses an alternative to the ADA and business necessity approaches. It follows the  
19 pattern of some states, such as Oregon, that permit testing for employee susceptibility or  
20 monitoring only with the consent of the employee.

21  
22 *Subsection (a)(3)*. This draft also incorporates another exception currently in some state  
23 statutes that allows testing to investigate a worker's compensation claim. (NH, NY). Utah has a  
24 new statute with an exception for testing when the employee has placed his or her health at issue  
25 in a proceeding, but only by order of a court or administrative agency after finding compelling  
26 need and that the information is otherwise unavailable.

27  
28 *Subsection (b)*. Once testing to determine susceptibility or monitoring is permitted, the  
29 issue becomes the permissible use of the data. To what extent should an employer be able to  
30 exercise paternalism and make employment decisions to prevent potentially harmful employee  
31 exposure based on the information obtained from testing? The way the federal statutes would be  
32 applied to this genetic information has not been tested in court and is not entirely clear. On one  
33 hand, in 1991 the Supreme Court held that a chemical company's policy barring women of child-  
34 bearing age from employment opportunities that involved exposure to lead violated Title VII  
35 prohibitions on gender discrimination. *International Union v. Johnson Controls*, 499 U.S. 187  
36 (1991). On the other hand, the ADA allows employers to act on health information, even in the  
37 case of disability, when there is a direct threat to the health or safety of others in the workplace.  
38 42 U.S.C. § 12113(b). In a case involving a worker's liver damage due to exposure to workplace  
39 solvents, the Court upheld EEOC's regulation interpreting this provision to apply when there is  
40 no risk to others but when an employer can show that an individual's disability poses a  
41 significant risk of harm to the individual. *Chevron v. Echazabal*, 122 S. Ct. 2045 (2002). The  
42 implication of this case is that without specific state legislation, an employer may make adverse  
43 employment decisions based on screening or monitoring requested by an employee. The current

1 draft follows the lead of a number of states that prohibit this use of genetic information.

2  
3 The Brush-Wellman company in Cleveland provides a model for the way in which a  
4 company could be permitted to use monitoring information. Brush Wellman conducts genetic  
5 tests for its employees who work with beryllium, but the testing is voluntary and confidential.  
6 Moreover, the test results are provided to the employee, who makes the decision on what action  
7 to take. The company takes no action against the employee as a result of the genetic testing.  
8 Cynthia Nance, Paul Miller, & Mark Rothstein, *Discrimination in Employment on the Basis of*  
9 *Genetics*, 6 Employee Rights & Employment Policy Journal 57, 64-65 (2002).

10  
11 **SECTION 104. PROHIBITION ON USES OF GENETIC INFORMATION.**

12 (a) An employer may not refuse to hire, discharge, or otherwise take an adverse  
13 action against an individual on the basis of:

14 (1) genetic information; or

15 (2) an individual's or individual's family member's request for genetic  
16 testing or use of genetic services.

17 (b) An employer may not disclose an individual's genetic information without the  
18 individual's written consent.

19 **Reporter's Notes**

20  
21 *Subsection (a)(1).* Many state statutes prohibit discrimination among employees or  
22 applicants for employment on the basis of genetic information. (Ark, Ill, Kan, LA, Maine, MD,  
23 Mass, Mich, MO, Neb, Nev, NJ, NY, NC, OK, OR, RI, SD, Tex). Even with limitations on  
24 access, no privacy protection is perfect. Thus even with access limitations in Section 103, it  
25 seems necessary to include an anti-discrimination provision as well, as done in a number of  
26 states. (MD, Mass, Mich, Minn, Neb, Nev, NY, OR, RI, Tex). The wording in this draft is based  
27 on a new Maryland statute, but is similar to the provisions in several states.

28  
29 An alternative formulation is used by other states that do not refer to discrimination, but  
30 rather ban the use of genetic information in employment. (Minn, NMex, UT, Vt, Va, WI). For  
31 example, New Mexico's 2005 statute provides simply that "[i]t is unlawful for a person to use  
32 genetic information in employment, . . ." Wisconsin and Minnesota prohibit "adverse  
33 employment actions" based on genetic information. In Utah, employers may not take into  
34 account genetic information about an individual in connection with an employment decision.

1 Some states make exceptions to their discrimination prohibition for business necessity,  
2 bona fide occupational qualifications (BFOQs) or inability to preform job duties. These are  
3 primarily states that use disability or employment discrimination statutes as a vehicle for their  
4 regulation of genetics in the workplace, but other states have made this exception as well. (Cal,  
5 Hawaii, Maine, Mass, Mi, MO, Neb, NY). As discussed in the notes to Section 103, the ADA  
6 permits adverse employment decisions against individuals with disabilities when employee safety  
7 is endangered. Some states have restricted this exception when it is based on genetic information  
8 to the circumstance where an employee voluntarily provides the genetic information. (Mich,  
9 Neb).

10  
11 An argument can be made that protection for genetic information as defined in this draft  
12 is too wide because it would encompass decisions an employer might make based on an  
13 individual’s current medical condition. *See, e.g.,* Henry T. Greely, *Genotype Discrimination:  
14 The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1503 (2001). An  
15 alternative would be to rely on existing law for protection of individuals with genetic diseases  
16 that have become manifest and limit the restrictions on use of genetic information to predictive  
17 information. This could be done easily using the definitions in this draft by substituting  
18 “predisposing genetic characteristic” for “genetic information” in subsection (a)(1).

19  
20 *Subsection (a)(2).* The provision concerning an individual’s request for testing or use of  
21 information is drawn from states that prohibit discrimination based on requests for or use of  
22 genetic services. (LA, Maine, NC, VT). Alternatively, this limitation could be accomplished by  
23 including “request for genetic testing” within the definition of “genetic information.” (RI).

24  
25 *Subsection (b).* In addition to prohibiting the use of genetic information as a basis of  
26 discrimination or for employment decisions, some states also protect against the disclosure of  
27 such information by employers, as in subsection (b) of the draft. (Ariz, Fla, LA, Mass, NH, NJ,  
28 Or, RI). This provision is consistent with a privacy rationale for protecting genetic information.  
29

## 30 **SECTION 105. REMEDIES AND ENFORCEMENT.**

31 (a) Individuals who claim a violation of section 102 or subsection 104(b) may file  
32 a civil suit for compensatory [or statutory] damages.

33 (b) Individuals who claim a violation of section 104 may file a claim with the  
34 [state civil rights agency]. If the agency issues a “right to sue notice,” the individual may file a  
35 civil suit for back pay, reassignment, reinstatement, or compensatory damages.

### 36 **Reporter’s Notes**

1           Most states require that employees submit claims of unlawful employment discrimination  
2 to a state agency or the federal Equal Opportunity Employment Commission. States otherwise  
3 rely on a mixture of administrative and civil processes, although a few have enacted criminal  
4 penalties. This draft allocates remedies and enforcement according to whether the violation  
5 involves obtaining or disclosing genetic information in violation of an employee’s privacy or  
6 involves discriminatory use of such information.

7  
8           Using a state employment discrimination agency may make sense for enforcement of  
9 provisions related to employment decisions because such agencies already have the apparatus in  
10 place to enforce state civil rights and disability statutes.

11  
12           For privacy violations, such agencies do not have expertise in controlling the flow of  
13 information. Enforcement could be turned over to an agency with that expertise or to civil  
14 actions by aggrieved individuals. Moreover, the typical remedies for employment discrimination  
15 are not necessarily appropriate for a privacy violation. A privacy rights perspective assumes an  
16 intrinsic harm from the invasion of privacy, whether or not consequential damages are incurred.  
17 Because of difficulties in measuring damage to privacy interests, statutory damages might be  
18 appropriate.



1 **ARTICLE 2**

2 **HEALTH INSURANCE**

3  
4 **SECTION 201. DEFINITIONS.**

5 (1) "Family member" means an individual's spouse or partner, an individual's  
6 dependent child, and all individuals related by blood to the individual, spouse, or dependent  
7 child.

8 (2) "Genetic information" means information about an individual's genetic tests,  
9 the genetic tests of an individual's family member, or the diagnosis of a disease or condition in  
10 an individual's family member.

11 (3) "Genetic services" means a genetic test, genetic counseling, or genetic  
12 education.

13 (4) "Genetic test" means an analysis of human genetic material, including DNA,  
14 RNA, chromosomes, proteins, and metabolites that detects genotypes. It does not include routine  
15 physical examinations.

16 (5) "Insurer" means an entity that provides health insurance.

17 (6) "Predisposing genetic characteristic" means a genetic marker on an  
18 individual's genes or chromosomes that is determined from genetic information and is associated  
19 with a statistically significant increased risk of developing a disease or medical condition for  
20 which the individual is asymptomatic.

21 **Reporter's Notes**

22 The definitions are identical to those used for Article 1 on employment.  
23

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26

**SECTION 202. APPLICABILITY.**

(a) This Article applies to the following types of insurance:

(1) a health insurance policy issued, delivered, or renewed in this State that is written on an individual basis, a group basis, a franchise basis, or a blanket basis;

(2) a group or individual contract through which a health maintenance organization furnishes health care services that is delivered, executed, or renewed in this State;

(3) a health care plan of a state or local governmental entity that provides coverage for health care services on a self-insurance basis in this State; and

(4) a self-funded employee welfare benefit plan to the extent permitted by ERISA.

(b) This Article does not apply to any of the following: accident-only insurance, credit insurance, disability income insurance, life insurance, worker’s compensation insurance, automobile medical payment insurance, or coverage issued as a supplement to liability insurance.

**Reporter’s Notes**

This section is included to provide the drafting committee with a list of the types of health insurance that could be covered by this article. The list is drawn from the Indiana statute. An alternative would be to incorporate this information into the definition section.

The section closes the gaps left by HIPAA in that it applies to small groups and individual coverage.

**SECTION 203. ACCESS TO GENETIC INFORMATION; PRIVACY.** An insurer

may not:

(a) require an individual or an individual’s family member to take a genetic test;

1 or

2 (b) disclose an individual’s genetic information without the individual’s written  
3 consent.

4 **Reporter’s Notes**

5  
6 This section combines the privacy provisions that are common to many of the state  
7 statutes.

8  
9 **SECTION 204. LIMITATIONS ON USE OF GENETIC INFORMATION.** In

10 determining eligibility for coverage, establishing premiums, limiting coverage, renewing  
11 coverage, terminating coverage, or making other underwriting decisions in connection with the  
12 offer, sale, continuation, or renewal of a health insurance policy, an insurer may not:

13 (a) request an individual, directly or indirectly, to provide genetic information;

14 (b) inquire whether an individual or an individual’s family member has taken or  
15 refused to take a genetic test.

16 (c) consider an individual’s genetic information.

17 **Reporter’s Notes**

18  
19 This section reflects and combines the approach of many states that prohibit the use of  
20 genetic information for setting eligibility requirements and for underwriting. It partially closes  
21 the gaps left by HIPPA in that it extends beyond merely prohibiting complete denial of coverage;  
22 the section also prohibits use of genetic information in determining coverage and establishing  
23 premiums.

24  
25 There are many alternatives. Some other states take an approach like that of HIPPA and  
26 use a non-discrimination provision that prohibits higher premiums than those charged to  
27 similarly situated individuals. (Alaska, Ark, Ill, Iowa). Yet other states prohibit the use of  
28 genetic information for underwriting health insurance without actuarial justification. (Ariz,  
29 WV). In some states, use of genetic information for risk selection is permitted if an individual  
30 submits the information voluntarily or if the information is favorable to the individual. (Ill, Ind,  
31 Mass, Mo, NY). Yet other states regulate this use by prohibiting insurers from increasing policy

1 rates based on genetic information. (Md, Mont, Or, Tex).

2  
3 This section illustrates some of the problems with treating genetic information as a  
4 distinct category of medical information. First, the section offers less protection than HIPPA in  
5 terms of eligibility decisions for individual and small group coverage because it regulates use of  
6 genetic information only, not information on all medical conditions. Second, it is often  
7 permissible for insurers to consider existing medical conditions in determining coverage and  
8 premiums under other law so long as they treat like situations alike. This Section would impose  
9 a different standard with regard to conditions predicted by genetic information, thus raising the  
10 practical question of which conditions are “genetic.” Even conditions with a genetic component  
11 are rarely entirely “genetic.”  
12

13 The prohibition on considering an individual’s genetic information in this Section is  
14 consistent with the policy treatment in use of information in the employment context in Section  
15 104. However, as in that section, an argument can be made that protection for genetic  
16 information as defined in this draft is too wide. As discussed above, the prohibition would create  
17 a different standard for genetic illnesses than for other medical conditions. Many think that this  
18 would place too great a burden on insurers. *See, e.g.,* Henry T. Greely, *Genotype*  
19 *Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483,  
20 1503 (2001). An alternative would be to limit the restrictions to predictive information by  
21 substituting “predisposing genetic characteristic” for “genetic information” in subsection (c).  
22

23 **SECTION 205. PREEXISTING CONDITION EXCLUSION.** An insurer may not  
24 treat a predisposing genetic characteristic as a preexisting condition for purposes of limiting or  
25 excluding benefits or coverage based.

#### 26 **Reporter’s Notes**

27  
28 This section reflects the approach of states that do not permit health insurers to impose  
29 preexisting condition exclusions based on predictive genetic information in the absence of a  
30 diagnosis based on symptoms of the disease or condition. (Alaska, Conn, Idaho, Iowa, Ky,  
31 others).  
32

#### 33 **SECTION 206. PERMITTED INFORMATION.**

34 (a) If a claim for payment for health care services has been made against an  
35 individual’s health insurance policy, an insurer may request:

1 (1) information regarding the need for a genetic test, but not the results of  
2 the test, when the service rendered is a genetic test;

3 (2) the portion of genetic information necessary to determine the insurer's  
4 obligation to pay for health care services when the primary basis for rendering the services is a  
5 genetic test.

6 (b) An insurer may store genetic information obtained under this subsection only  
7 as provided in the Health Insurance Portability and Accountability Act of 1996.

8 **Reporter's Notes**

9  
10 This section highlights the potential role for genetic information in providing payment for  
11 genetic tests and health care services. It is modeled on a Utah provision.  
12

13 **SECTION 207. ENFORCEMENT.**

14 (a) The [State Commissioner of Insurance] shall enforce this Article.

15 (b) A violation of this Article is an unfair and deceptive insurance act or practice  
16 under [cite insurance code].

17 **Reporter's Notes**

18  
19 This is a simplified version of the enforcement provisions in several different statutes.

1 **ARTICLE 3**

2 **LIFE, DISABILITY, AND LONG-TERM CARE INSURANCE**

3  
4 **SECTION 301. DEFINITIONS.**

5 (1) “Family member” means an individual’s spouse or partner, an individual’s  
6 dependent child, and all individuals related by blood to the individual, spouse, or dependent  
7 child.

8 (2) “Genetic information” means information about an individual’s genetic tests,  
9 the genetic tests of an individual’s family member, or the diagnosis of a disease or condition in  
10 an individual’s family member.

11 (3) “Genetic services” means a genetic test, genetic counseling, or genetic  
12 education.

13 (4) “Genetic test” means an analysis of human genetic material, including DNA,  
14 RNA, chromosomes, proteins, and metabolites that detects genotypes. It does not include routine  
15 physical examinations.

16 (5) “Insurer” means . . .

17 (6) “Predisposing genetic characteristic” means a genetic marker on an  
18 individual’s genes or chromosomes that is determined from genetic information and is associated  
19 with a statistically significant increased risk of developing a disease or medical condition for  
20 which the individual is asymptomatic.

21 **SECTION 302. APPLICABILITY.** This Article applies to group [and individual]  
22 insurance policies for life, disability income, and long-term care.

1 **Reporter's Notes**

2  
3 The applicability of the Article to group or individual insurance or both is a major issue.  
4 An alternative to a separate applicability section would be to incorporate this information into the  
5 definition section.  
6

7 **SECTION 303. ACCESS TO GENETIC INFORMATION; PRIVACY.** An insurer

8 may not:

9 (a) require an individual or an individual's family member to take a genetic test;

10 or

11 (b) disclose an individual's genetic information without the individual's written

12 consent.

13 **Reporter's Notes**

14  
15 This section combines the privacy provisions that are common to state statutes that forbid  
16 insurers from requiring genetic tests and regulate the terms under which an insurer may disclose  
17 the results of voluntary tests. (Cal, Mass, Minn, NY, Or, Vt).  
18

19 **SECTION 304. LIMITATIONS ON USE OF GENETIC INFORMATION.** An

20 insurer may not use genetic information about an individual's predisposing genetic  
21 characteristics in determining eligibility for coverage, establishing premiums, limiting coverage,  
22 renewing coverage, terminating coverage, and other underwriting decisions in connection with  
23 the offer, sale, continuation, or renewal of an insurance policy unless:

24 (a) an applicant for insurance submits genetic information to an insurer; and

25 (b) the applicant's medical condition and history and the insurer's claims

26 experience or actuarial projections establish that substantial differences in claims are likely to  
27 result from the applicant's predisposing genetic characteristics.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14

**Reporter's Notes**

This section follows the example of states that require an actuarial justification for using genetic information in denying coverage and underwriting for one or more of the types of coverage in regulated in this Article. (Ariz, Kan, Maine, Md, Mass, Mont, NJ, NMex, Vt, Wis).

Alternatively, a few states provide stronger regulations for disability insurance. Kansas and Wyoming appear to prohibit entirely the use of genetic information in determining eligibility and in underwriting. In Arizona, genetic information cannot be used as a basis for rejecting an applicant for coverage.

This Section is narrower than the restrictions on use of genetic information in employment and health insurance in that it applies only to predisposing genetic characteristics.

15  
16  
17  
18

**SECTION 305. PREEXISTING CONDITION EXCLUSION FOR DISABILITY**

**INSURANCE.** In connection with providing insurance for disability income, an insurer may not treat a predisposing genetic characteristic as a pre-existing condition for purposes of limiting or excluding benefits or coverage.

19  
20  
21  
22  
23  
24

**Reporter's Notes**

This section follows the example of Idaho and Wyoming by prohibiting disability insurance from treating a genetic characteristic that establishes only an increased risk of a disease as a preexisting condition. The individual must be symptomatic with the disease.

25  
26  
27  
28

**SECTION 306. ENFORCEMENT.**

(a) The [State Commissioner of Insurance] shall enforce this Article.

(b) A violation of this Article is an unfair and deceptive insurance act or practice under [cite insurance code].